

OPTIMIZING CARE
SYSTEMS FOR PEOPLE
WITH INTELLECTUAL
AND DEVELOPMENTAL
DISABILITIES: A
WORKSHOP
NATIONAL ACADEMIES
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ENGINEERING, AND
MEDICINE
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Models of Care

“Every system is perfectly constructed to produce the results it achieves.”

Peter Senge, *The Fifth Discipline*, 1990

Health Care System for People with IDD

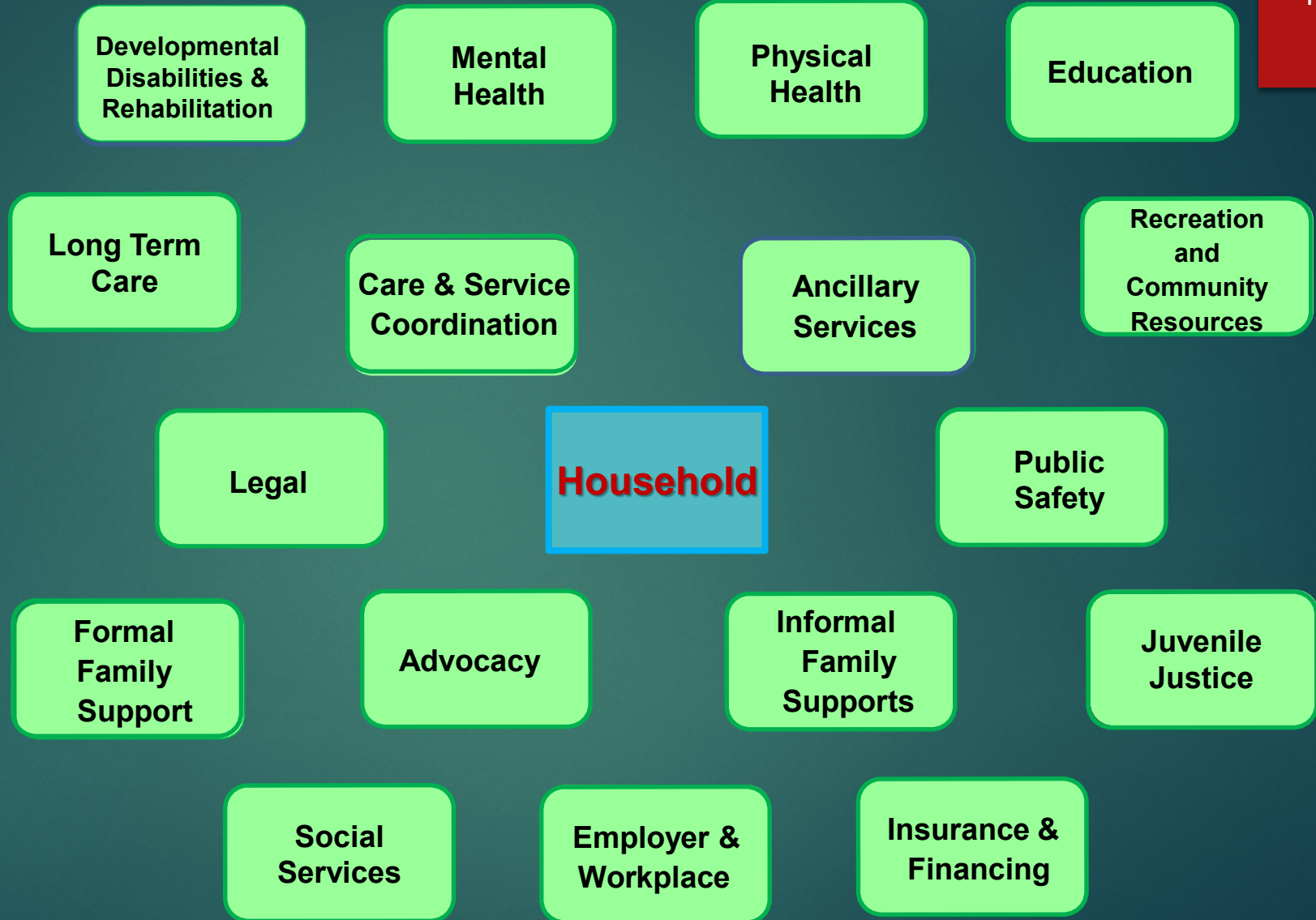
The Problems

- ▶ Health Care and Health Disparities
- ▶ Patient & Caregiver Dissatisfaction with Care
- ▶ Unreliable Quality of Care

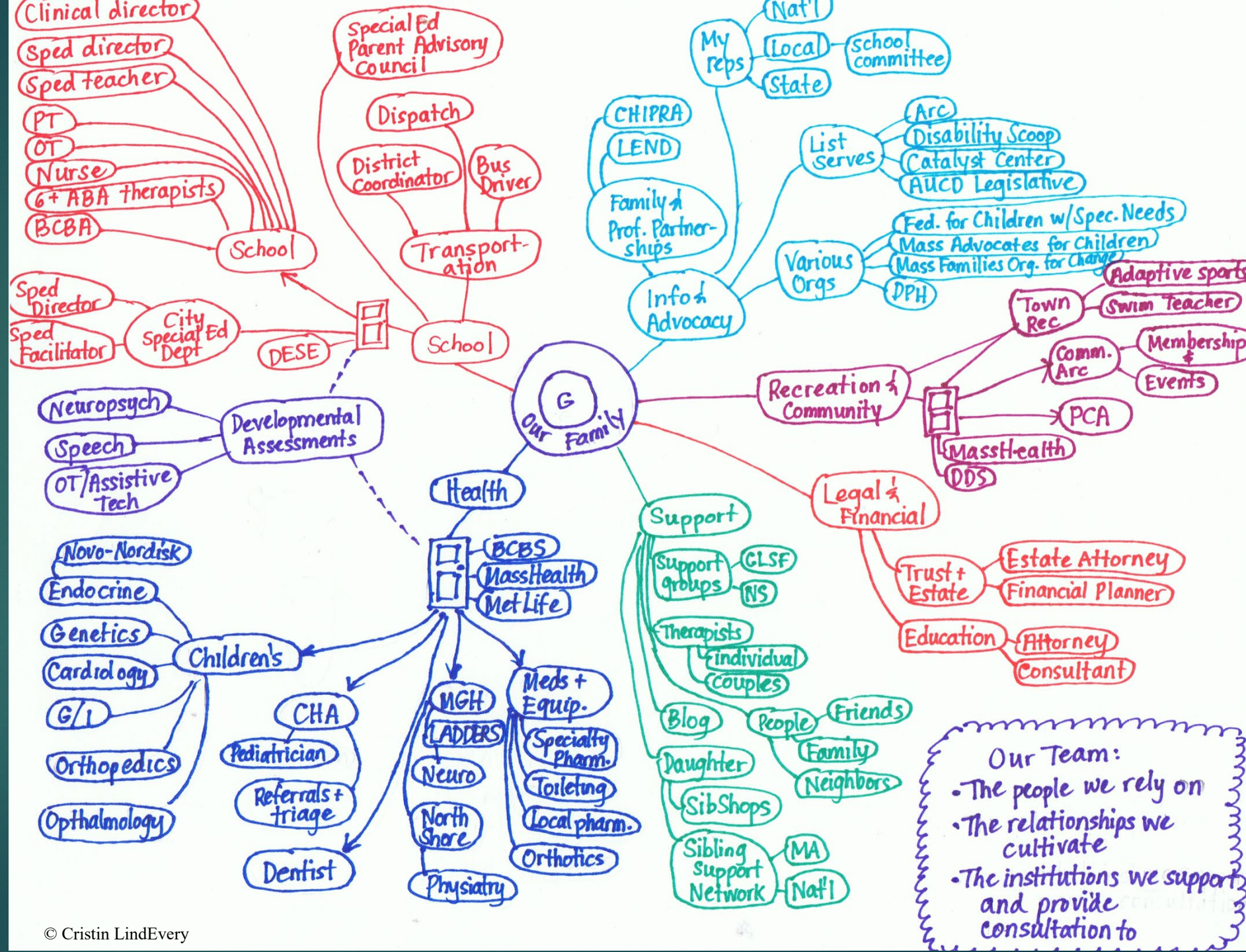
Drivers -- Clinicians and Systems Fail to:

- ▶ Understand the Special Needs of People with IDD
- ▶ Design Care to Align with the Special Needs, Goals, & Priorities of People with IDD
- ▶ Recognize their Limited Capacity to Address Special Needs of People with IDD

A system is a set of mutually dependent, interacting elements that accomplish a desired objective



Care Plans:
Every patient
should have
one





Special Needs of People with IDD

6

- ▶ High use of services and medication
- ▶ Prevalent co-morbid chronic conditions: medical, cognitive, and socio-emotional
- ▶ Dependence on specialty care
- ▶ Frequent unmet medical, mental health, and dental needs
- ▶ Difficulty processing health information, communicating with health professionals, and retaining information
- ▶ Susceptible to abuse and neglect
- ▶ Caregiver stress

Criticisms of Clinical Care (Short List)

- ▶ Physicians not trained to care for people with IDD
- ▶ Care not aligned with patient's needs, goals, and priorities
- ▶ Care not developmentally or cognitively appropriate
- ▶ Poor communication and provision of information
- ▶ Referrals difficult to obtain
- ▶ Poor coordination within health care and across sectors
- ▶ Do not regularly refer for peer support
- ▶ Little planning for transition from pediatric to adult care
- ▶ Inadequate focus on quality-of-life issues

Essential Capacities of IDD Practices

8

Medical Home = Patient/Family-Centered, Community-Based, Comprehensive, Coordinated, Accessible, Compassionate, Continuous, Developmentally, Cognitively, and Culturally Effective Care provided by a Multi-Disciplinary Team.

- Assessment-based care planning & monitoring
- Life course health care and transition planning
- Functional assessment
- Adequate time
- to peer and family support
- Medication management
- Individualized, primary contact in the practice
- Technology: telehealth, electronic medical records
- Linkages to and coordination with frequently used resources, programs, social and mental health services
- Linkages Individual patient advocacy, e.g., IEP participation
- Continuous quality improvement

Core Components of Care System for Individuals with IDD

- ▶ Screen for eligibility and do outreach for enrollment
- ▶ Equitable access to assessment-based, comprehensive, evidence-based care
- ▶ Medical home certification for primary care practices
- ▶ Adequate, trained primary care and referral network
- ▶ Patient-professional partnerships at the system and practice levels
- ▶ Planned and facilitated transition from pediatric to adult care
- ▶ Health information technology to support individual care and population health
- ▶ Well-defined metrics for ongoing quality assurance & improvement
- ▶ Insurance & financing to minimize family financial burden and maintain needed benefits
- ▶ Adequate payment for team-base care, care coordination, dental and mental health services
- ▶ Whole family care including addressing social determinates of health and family quality of life

Actions Systems Could Take to Improve Care for People with IDD

- ▶ Measure performance and provide feedback to practices
- ▶ Transparent quality reports including achievement of patient-specific goals
- ▶ Support education and technical assistance to improve care for special populations
- ▶ Incentivize medical home certification
- ▶ Prevent secondary disabilities and promote well-being of patients and families
- ▶ Provide adequate payment for comprehensive, coordinated care
- ▶ Underwrite the costs of adopting health information technologies
- ▶ Foster systemwide adoption of best practices